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ABSTRACT

This report on "Options for Individuals" is part of a series documenting innovative supports for community living for adults with severe disabilities. Options for Individuals, which began in 1984 in Kentucky, uses Medicaid waiver funding to support 29 people with severe and often multiple disabilities during the day. While the program is based at a facility, the agency has a long history of creative community-building efforts that they have used to get people involved in meaningful activities and relationships outside of the facility. In doing so, they have facilitated peoples involvement in paid and volunteer work, varied leisure interests, and social engagements. This report, based on a site visit in June 1997, documents the positive community-building efforts used by Options to create meaningful daytime opportunities and connections for the people they support. It describes key strategies Options uses to promote community participation and relationships, including recognition of the importance of place, active involvement in facilitating the development of relationships, focus on variety of peoples daytimes, use of an in-depth person-centered planning process, and long-term commitment to people. The experiences of three clients are highlighted. The report also discusses some of the challenges faced in relation to these efforts. (CR)

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CREATING MEANINGFUL DAYTIMES: COMMUNITY BUILDING AT OPTIONS FOR INDIVIDUALS, LOUISVILLE, KENTUCKY

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Pam Walker

Center on Human Policy

March 1998

Please note that all names used throughout this report are pseudonyms.

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Options for Individuals, which began in 1984, supports 29 people, labeled as having severe and often multiple disabilities, during the day, with Medicaid waiver funding. While the program is based at a facility, the agency has a long history of creative community-building efforts that they have used to get people involved in meaningful activities and relationships outside of the facility. In doing so, they have facilitated people's involvement in a broad range of daytime activities, including paid and volunteer work, varied leisure interests, social engagements. At the same time, in recent years, these efforts have been scaled back due to financial limitations and staffing cutbacks, challenges faced by many other agencies across the country.

The purpose of this report, based on a site visit in June 1997, is to document the positive community-building efforts used by Options to create meaningful daytime opportunities and connections for the people they support. The report also discusses some of the challenges they face in relation to these efforts.

Background

When Options started, in order to begin thinking about how to support people, they took a close look at people's lives. Most of the people they support, who currently range in age from 20s to 50s, live with their families. Many of them have significant

personal care needs. Overall, the people they support have experienced a high degree of segregation, with a distinct lack of community participation. Even though most have lived in the community, they have been very isolated and disconnected from the community.

According to the director, their past experiences with the service system have been highly negative. They were defined in terms of deficits versus competencies or capacities. Supports were focused on skill development, versus helping people to become known and participate in community life. They typically had few, if any, places they could go in the community where people knew them and would be glad to see them. Their family members needed support and relief, but at the same time were fearful about the future for their family member.

Based on these experiences, Options' aim, since its inception, has been to approach people from a different perspective--based on capacities rather than deficits--and build on this to create opportunities for integrated community participation and relationships. The previous director developed a strong value base in support of this at the agency, as well as many materials, still used by the agency, to keep them on track, asking the right questions and looking comprehensively at aspects of people's lives that would help enhance capacities and create opportunities for a sense of community. Their mission statement describes Options as a program that: (1) encourages each individual to grow and develop according to his/her own capacities; (2) fosters family stability; (3) promotes meaningful community involvement and social growth; and (4)

encourages each individual to offer his or her unique gifts and talents to the community.

The following section of this report describes some of the daytime supports Options provides to individuals. The next section discusses key promising practices of the agency, and a concluding section addresses current and future challenges.

Moving Toward Integrated Daytimes

Options supports people, for 35 hours a week, in three types of ways: (1) individualized interests and community-building; (2) small-group community activities; and (3) on-site activities at their facility. During a given day, all individuals come into the facility in the morning. Then, for the morning, some individuals go out to pursue individualized interests, some go out in small-group activities, and some remain on-site. Most people come back to the facility for lunch. In the afternoon, people switch to a different type of activity from the morning (e.g., from small-group in the morning to individualized pursuit in the afternoon). Finally, everyone returns to Options at the end of the day, before going home. During the course of a week, all individuals have at least a few opportunities for individualized pursuits and a few opportunities for small-group activities, in addition to time on-site.

Individualized interests and community-building. Over the years, Options' focus has been on getting people out of the building. They do this as much as possible through the individualized "community-building" approach, with staff assisting a particular person to spend time in places of interest to him or her, to find meaningful things to do during the day, and to form special connections and relationships. Some of

the types of places and activities people participate in, as workers and patrons, include cafes and diners, libraries, college campuses, gyms, churches, and childcare centers, among others.

Small-group activities. Because of staff and funding limitations, Options cannot exclusively utilize the individualized community-building approach. Thus, they rely on small groupings (of up to three people) for other community activities, such as volunteering at Meals on Wheels, the Red Cross, or playing Bingo. One staff person commented that typically "this mostly creates community presence for people, rather than community building, but sometimes nice connections happen."

On-site activities. Among the on-site activities is an arts program that is unique as compared to many traditional art therapy activities in day habilitation programs. The arts program has forged numerous connections, for various individuals and the agency, with the broader community. For example, a number of individuals have shown pieces in several local galleries. In addition, some individuals have artwork displayed in other community places where they are known (e.g., a community center, a barber shop).

Primarily through the community-building approach, staff have been able to help create daytimes for people that include a variety of activities and involvements, from paid work, to volunteer work, to leisure and social activities. Some examples are briefly described below.

Mark. In the past, Mark enjoyed going to malls and bowling. Apart from that, however, he didn't express much enthusiasm for anything, and staff report it was "hard

to keep his spirits up." Over time, staff at Options have worked to build a wider variety of activities and opportunities into Mark's day and week. He now has two jobs--4 hours a week at McDonald's and 6 hours a week at Papa John's Pizza. Part of his job at McDonald's is to pack "special meals," and at Papa John's he spends some time folding pizza boxes, among other things. Options' staff have assisted Mark to learn these routines over a few months. Now, Mark does these tasks by himself, and Options' staff no longer accompany him all the time to these work sites. However, they periodically check in with Mark and his employers to see how it is going. In addition to work, staff have Options have supported Mark to become involved in the choir at his church. He rehearses with them on Wednesday evenings, and sings with them at Sunday services. With small groups from Options, Mark regularly shops for groceries, as well as spends time at malls and engaged in miscellaneous community activities.

Like an increasing number of people who Options supports, they have assisted him with residential support, as well. Mark's family originally wanted him placed in a congregate facility; however, they did not stand in the way of the agency electing to pursue an alternative. Thus, Mark currently shares an apartment with Andy, who lives there rent-free in exchange for support of Mark. For instance, Andy is assisting Mark to get to know some people in their neighborhood through use of the laundromat and other shops and services. While Mark still sometimes has his times of "low spirits," overall, as a result of Options' efforts, he now has more activities and interests in his life than in the past, and agency staff continue to make seek ways to expand his opportunities and connections.

Stacy. Stacy currently lives with her parents, who have provided most of the support for Stacy, with some assistance from her siblings and their spouses. Options has been working with Stacy on expanding her community activities as well as relationships. She has a few regular activities built into her week now--going to the gym twice a week, getting her nails done once a week, and spending some time at the local library. Stacy especially enjoys going out for lunch, so staff have worked to find some regular lunch partners for Stacy--they currently include a former Options' staff member, a former neighbor, a person from her church, and her brother. With a group, during the week, Stacy spends time at a grocery store, a laundromat, and volunteering at a church, among other things.

Stacy's parents have been supportive of Options' efforts to develop integrated daytime activities. At the same time, they feel it is important to have a facility as a base for Options' operation. Similarly, though a move out of their home is not imminent, in planning for her future, they are not comfortable relying on a nonfacility-based program, and have placed Stacy on a waiting list at a residential facility.

Fred. Fred is someone whom the agency has found very challenging to support. He can be very loud and aggressive, and staff have at times been afraid of him, as well as self-conscious about his behavior. While Fred occasionally has outbursts in the community, it is very clear that is anger escalates when he spends time in the facility versus the community.

Despite the challenges of supporting Fred, in the past several years at the agency, staff had worked to help create some very positive community connections for Fred.

He spent time helping out at a car dealership and, over time, developed a close relationship with the owner, Bill. In addition, at a craft shop, he became friends with the couple who operated it, Bob and Tina. Eventually, however, Bill died, and Bob and Tina moved out of town. Thus, Options staff are now in a position of needing to help create some new community connections for Fred. He currently is spending time with a few different staff members "hanging out" in the community, for example, at an ice cream shop, two cafes, and a park, seeking possible interests to pursue. He also spends time twice a week volunteering at Meals on Wheels.

Based on the experience of supporting the above people and many others, over the years, a number of key positive practices can be identified from the work of Options. These are described below.

Positive Practices in Community-Building

There are a number of key strategies used at Options which have provided a foundation, over the years, for their efforts to promote community participation and relationships. These include: recognition of the importance of place; active involvement in facilitating the development of relationships; focus on variety of people's daytimes; use of an in-depth person-centered planning process; long-term commitment to people. Each is discussed briefly.

Recognition of the importance of place. It is significant that staff at Options are not just content to help people spend time in any community places. They realize that the nature of these community places, and the opportunities available, or lack thereof, make a tremendous difference in the person's community experience. They have a

number of strategies for promoting participation in meaningful community places. For example, they spend time with people in their neighborhoods and broader community exploring to see what kinds of places exist, and in getting to know people in some of these places. At staff meetings and during individualized planning processes, time is spent reflecting on the types of places people go, and the types of interactions and possibilities for relationships that exist in these settings. For example, Keith has been spending some time each week at Marty's Sporting Goods for 12 years now. In the past, Keith interacted with Marty and his wife at the store; in addition, he would go to their home on occasion for various social gatherings. However, it was Marty's wife who primarily initiated interaction in the store and organized the gatherings in their home. Since Marty and his wife separated, and she no longer comes to the store, Kevin seems to have significantly less interaction in the score and no longer is connected to either of them outside of the store. Thus, agency staff are relooking at Marty's Sporting Goods as a place for Keith to spend time in order to see whether other relationships can be developed there or to determine whether they should explore some additional places for Keith to spend time.

Active involvement in facilitating the development of relationships. Over the years, staff at the agency have learned that relationships do not always happen naturally. Thus, they play an active role in assisting people to develop and sustain relationships. After a time, they may back off from some of this involvement; however, they feel it is important to remain connected in same way--at least aware of what is going on and available to step in and give support. At the same time, they realize that

they need to let go of control of these relationships, without trying to orchestrate every interaction or smooth over every difficulty. With respect to looking at relationships in people's lives, they focus on the quality of these relationships, rather than the quantity. One of the guides they use to do this, a document developed by the previous director of Option, is entitled, "Questions to Ask Over Time Regarding the Quality of Community Connections." Finally, a strength is that they openly acknowledge that they, as an agency, don't have all the answers about how best to build relationships and community connections in people's lives.

Focus on variety in people's daytime. It is positive that Options has a focus on creating a variety of opportunities in people's daytimes, not just work. They feel that work should not be the primary focus for everybody; at the same time, they feel that they could do a better job of helping some people find work opportunities. For those who may not have an interest in working, such as Mark, initially, staff encourage them to try some different work experiences in order to find a positive one.

The people who Options supports in paid work do not work full time. Thus, for these people, and for others the agency supports who don't have paid work, staff make an effort to build in a variety of experiences during their daytime, including, possibly, volunteer work, leisure activities, and social interactions. When Options staff explore possible places for people to work or spend time engaged in other activities, they focus on finding places that will provide not just a job or activity, but real opportunities for relationships.

Use of an in-depth person-centered planning process. Over time, the agency has developed a comprehensive, individualized planning process. As a tool for this, they use "Mapping," a graphic illustration for many areas of a person's life. For example, they do "maps" on such areas as: relationships in a person's life, personal history, places a person spends time for during the day, community places the person spends time, dimensions of home for the person, personal preferences, capacities, choices, respect, communication/relationship building capacities of the person, and vision/dreams. For each of these areas, the agency has detailed guidelines of questions to ask to get at key issues related to promoting quality community experiences and relationships. It is also notable that, over time, agency staff have remained open to learning more about people. As one staff member put it, "Getting to know people never ends."

Long-term commitment to people. Agency staff have demonstrated significant commitments to people they support. They have stuck by people through many ups and downs in their lives. In doing so, they have learned about the fragility of some connections, as they have seen some relationships end for various reasons and have then gone on to work to build new ones. For example, for years, Leslie spent time at a diner, where a key relationship was with Marion. Eventually, Marion retired and Leslie no longer goes to the diner and has little contact with Marion. Catherine went to a beauty salon for 11 years, where she had a significant relationship with Becky, who recently died. Thus, for these women, and others, agency staff are now at work trying to build new relationships into their lives.

Staff members' commitment to people they support is based on close, caring relationships in which they try to minimize their "power over" people. Based on these relationships, staff celebrate people's accomplishments and satisfactions and share their frustrations, anger, and pain. This commitment drives them to be concerned about all areas of people's lives, not just daytime, as discussed further below.

Present and Future Challenges

In the past year or so, the agency has faced some significant challenges to doing the types of community-building efforts described above. These challenges are not unique to Options, but rather are common to many agencies across the country. In the face of tighter funding, agencies are faced with decisions about financial cutbacks, decisions about maintaining facilities, and pressures or commitments to provide more services. Each issue is discussed below.

Financial cutbacks. In response to tightening funds, the agency cut back on both the number of staff and their community-building efforts. While the agency had been planning to decrease staff hierarchy within the agency has a whole, the loss of a few staff who coordinated and supervised some of the community-building efforts, without simultaneous restructuring of all staff roles, has diminished the agency's community-building capacity. The remaining staff, feeling the pressure of supporting more people with less staff, have decreased the amount of time they spend together consciously reflecting and brainstorming about community-building efforts. There is less time and energy of supervisory staff for mentoring newer staff regarding both agency vision and strategy. Thus, with less staff, who focus less on community-building, people who are

supported by the agency are having to spend more time in the facility or in group activities than in individualized community pursuits. According to the director, at one point in the past, everyone was scheduled out of the facility in both the morning and the afternoon. Now, he estimates that people spend about a little more than half of their time out of the facility.

In response to this money crunch, the agency is trying to figure out how best to gain additional financial resources. One of their thoughts is to expand the number of people they serve in order to have more discretionary funds at their disposal. However, at the same time, this solution is problematic for them. Growth in agency size may create what seem like short-term solutions; on the whole, however, Options, as well as many other smaller agencies around the country, recognize that smaller agencies, versus larger ones, have greater capacity to provide individualized, personalized supports.

Decisions about maintaining the facility. According to the director, if they were starting the program over again today, they would not choose to have it based in a facility. At the same time, when they have talked about closing it down, they have faced significant opposition from families of some of the people they support. As a result, they have chosen to keep the facility open for the time being, but to help people get out of it as much as possible. Their vision is that, through these efforts, one day they will no longer need the building because "eventually people's connections with lead them out of the building." At the same time, in recent years, they have been making

more use of the facility, rather than less. Thus, this is a clear example of the possibilities of fallback to increased use of facilities where they are in existence.

Need for more services. Many of the people they support live with parents who are now getting older. Currently, the parents are more in need of relief in the house, and are not able to assist the son or daughter in getting out of the house much if at all. According to the director, the agency is "now more than we ever imagined supporting people in their homes." They are doing respite in parents' homes, and have put together some supported living situations, which they anticipate doing more of in the future, for those whose can no longer live with their parents or whose parents have died. The agency has entered into this greater involvement in people's lives because of their commitment to these people. At the same time, the energy necessary to support people in multiple areas of their lives draws energy away from the daytime supports. At some point, they may need to decide whether to support fewer people comprehensively, or to focus on daytime supports and advocate for the development of other providers for other supports.

Conclusion

There are not any single, simple solutions to these dilemmas. Since its inception, Options has been working toward a vision of community participation and membership for the people they support. Over the years, the path to this vision has been filled with both successes and challenges. As a result of their community-building efforts, they have witnessed both the transformative power of community connections, as well as the fragility of some of these connections. Based on this, they have learned

that community-building involves long-term, sustained commitment; and they have been willing, as an agency, to invest themselves in type of commitment.

In the coming years, in relation to their vision, it will be important for the agency to prioritize, to advocate, and to weigh and balance tradeoffs at each step. First, just as they assist individuals with disabilities to plan and prioritize for their lives, as an agency, they will need to plan and prioritize how best to expend limited energy and resources. Second, as they assist individuals with disabilities with interdependence and community connections, the agency, too, will have to rely on its connections with others, throughout the system and beyond, to advocate together for increased funding and regulatory flexibility that provides incentive for agencies to promote true community integration. And finally, as they assist individuals with disabilities to develop their capacities, at each juncture of decision making, they, as an agency, will need to weigh and balance the tradeoffs, making best guess judgments as to how various decisions will enhance or detract from their capacity to follow their vision of community connection and membership for the people they support. The lessons they have learned based on their past community-building efforts, as well as their commitment and the close relationships they have forged with individuals they support, will be the guides for them as they move forward.